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Assessing Quality of Life in Life-Threatening Illness: Evaluating the Content Validity and Response Processes of MQOL-E and QOLLTI-F in Swedish Patients and Family Caregivers

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Abstract

The McGill Quality of Life Questionnaire-Expanded (MQOL-E) and the Quality of Life in Life-Threatening Illness-Family Carer (QOLLTI-F) instruments are designed to evaluate the quality of life of patients nearing the end of life and their family caregivers, and can be used together as companion tools. Current validity frameworks highlight the importance of understanding response processes—the cognitive and emotional engagement of participants when completing questionnaires—which may be influenced by cultural adaptation and translation. This study aimed to translate MQOL-E and QOLLTI-F version 2 into Swedish and assess their content validity and response processes in a Swedish healthcare context. The study was conducted in two phases: (1) translation and cultural adaptation of the instruments, and (2) evaluation of content validity and response processes using cognitive interviews with 15 patients and 9 family caregivers. Participants were recruited from hemodialysis, cardiology, pulmonology, and specialized palliative care services within a Swedish county hospital. Eligible patients had life-limiting illnesses including advanced cancer, end-stage kidney disease, chronic obstructive pulmonary disease, or advanced heart failure, and were receiving outpatient, inpatient, or home-based care. Participants reported that the questionnaires addressed relevant and important aspects of quality of life. Although a few items required additional reflection, the instruments were largely clear and comprehensible. Minor revisions were implemented to resolve translation ambiguities. Respondents valued the reflective nature of completing the questionnaires, perceiving it as an opportunity to articulate feelings and experiences related to their situation. The Swedish versions of MQOL-E and QOLLTI-F v2 demonstrate content validity, linguistic fidelity, and cultural relevance. They may also serve as tools to facilitate meaningful discussions about quality of life between patients, family caregivers, and healthcare providers. Further investigation of the psychometric properties of these translations is recommended.

Keywords: Quality of life, Patients, Family caregivers, Instrument adaptation, Cognitive interviews, Content validity

Introduction

A central objective of palliative care is to improve the quality of life (QOL) for individuals with life-limiting illnesses and their families by preventing and alleviating suffering. Achieving this goal requires the timely identification of patient and family concerns [1]. Consequently, systematic assessment of QOL for both patients and family caregivers is essential [2]. Self-reported instruments are increasingly employed to detect physical, psychological, social, and spiritual care needs, monitor changes over time, and evaluate the effects of interventions [3]. However, few QOL measures have been designed specifically for palliative care that are applicable regardless

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of the underlying disease [4]. While numerous disease-specific tools exist [2], there remains a need for instruments suitable for palliative care populations across diverse diagnoses.

The McGill Quality of Life Questionnaire (MQOL) was originally developed in Canada in both English and French for patients facing life-threatening illnesses, independent of specific disease type [5, 6]. It is now widely recommended and used internationally in palliative care settings [2, 4]. Designed specifically for end-of-life contexts, MQOL captures existential well-being and addresses both positive and negative factors affecting QOL, while maintaining a manageable length to reduce respondent burden [5–7].

Growing interest in self-reported QOL instruments has led to translations of the original MQOL into approximately 20 languages. The questionnaire has been updated and validated as the MQOL-Revised (MQOL-R) [8], which evaluates four domains: physical, psychological, existential, and social, along with a single item measuring overall QOL. Recognizing that patients' conditions can change rapidly near the end of life, MQOL-R assesses QOL over a short timeframe of 48 hours.

An expanded version, the MQOL-Expanded (MQOL-E), was developed to incorporate additional dimensions that individuals with life-limiting illnesses identify as important, including perceptions of being a burden, environmental factors, cognition, and quality of healthcare [9–11]. MQOL-E consists of 21 items, including the overall QOL item, all scored on a 0–10 numeric scale with verbal anchors at each end. After reverse-scoring where necessary, a score of zero represents the worst possible state. An example item reads: "Over the past two days (48 hours) I felt: Physically terrible (0) vs. Physically well (10)" [12]. **Table 1** summarizes the content of MQOL-E.

Table 1. Description of the McGill quality of life questionnaire - expanded (MQOL-E)

Item no.	Dimension	Item content
Single item	Overall QoL	Overall QoL
1	Physical	Problems with physical symptoms
2		Physical state
3		Problems due to physical functioning
4	Psychological	Being depressed
5		Being nervous or worried
6		Feeling sad
7		Fear of future
8	Existential	Meaning in life
9		Achievement of life goals
10		Control over life
11		Feeling about oneself
12	Social	Communication with people I care about
13		Relationships with people I care about
14		Feeling supported
15	Burden	Feeling about how one's situation affects people I care about
16	Environment	Physical surroundings
17	Cognition	Clarity of thought
18		Memory function
19	Health care	Access to information
20		Availability of health care[a]
21		Quality of care

[a] Item 20 is excluded from the final published version of MQOL-E

The experiences of family carers are closely linked to the circumstances of patients nearing the end of life [13, 14], and their own quality of life (QOL) is consequently affected. Therefore, assessing QOL among family carers is essential. Family carers play a crucial role in providing care and supporting the organization of home-based palliative care, and they may also require support themselves [15].

The Quality of Life in Life-Threatening Illness – Family Carer version (QOLLTI-F) was developed as a companion instrument to MQOL-E and has undergone psychometric validation with caregivers of patients with cancer [16–18]. The instrument was informed by qualitative interviews in which family carers shared what aspects of life they consider most important for their own QOL. These interviews highlighted both the challenges and positive aspects of caregiving, which are reflected in the questionnaire.

QOLLTI-F consists of 17 items, along with a single overall QOL item, organized into seven subscales covering different domains: environment, patient condition, the carer’s personal state, outlook, quality of care, relationships, and financial concerns. A distinctive feature of QOLLTI-F is an item assessing the patient’s condition, as this significantly impacts the carer’s own QOL [17]. Similar to MQOL-E, all items are rated on a numeric scale from 0 to 10 with verbal anchors at each end. After reverse scoring, a value of zero represents the worst possible situation. For example, one item reads: “Over the past two days (48 hours) I had time to take care of myself: Never (0) vs. Always (10).” **Table 2** provides a summary of the QOLLTI-F v2 item content. The questionnaire has also been translated into approximately ten languages.

Table 2. Description of the quality of life in life-threatening illness - family carer/caregiver version (QOLLTI-F v2)

Item No.	Dimension	Item Content
Single Item	Overall QoL	Overall Quality of Life
1	Environment	Satisfaction with place of care
2		Privacy
3	Patient Condition	Distress related to patient condition
4	Carer's Own State	Control over life
5		Time to take care of oneself
6		Clarity of thought
7		Physical state
8		Emotional state
9	Carer's Outlook	Feeling about caring for the family member (patient)
10		Comfort from outlook, faith, or spirituality
11		Meaning in life
12	Quality of Care	Agreement with decision-making process for patient
13		Availability of health care[a]
14		Quality of care
15	Relationships	Interaction with patient
16		Interaction with other important people
17	Financial Worries	Stress due to financial situation

[a] Item 13 is excluded from the final version of QOLLTI-F v3

Palliative care aims to improve the quality of life (QOL) for patients with life-limiting conditions and their families by alleviating suffering and addressing concerns early [1, 2]. Accurate assessment of both patients’ and family carers’ QOL is essential to identify needs, track changes, and evaluate care interventions [3]. While disease-specific QOL instruments exist, tools that are applicable across palliative care populations regardless of diagnosis remain limited [4].

The McGill Quality of Life Questionnaire (MQOL), initially developed in Canada in English and French, provides a comprehensive measure for individuals facing end-of-life situations, regardless of their underlying illness [5, 6]. MQOL assesses existential wellbeing and captures both positive and negative aspects of life, while remaining concise to avoid participant burden [7]. The instrument has been widely translated and recently updated to MQOL-Revised (MQOL-R), which evaluates physical, psychological, social, and existential domains, including a single overall QOL item and a 2-day recall period [8]. The expanded version, MQOL-Expanded (MQOL-E), incorporates additional domains identified as important to patients, including cognition, feelings of being a burden, environment, and quality of healthcare. The MQOL-E comprises 21 items, each scored 0–10 with verbal anchors, and includes one item assessing overall QOL [9, 10].

Family carers’ QOL is closely linked to the patient’s situation and significantly impacts caregiving and the organization of home palliative care [13–15]. The QOLLTI-F (Quality of Life in Life-Threatening Illness—Family carer version) was developed to capture carers’ perspectives and experiences, based on qualitative interviews highlighting both burdens and positive aspects of caregiving [16–18]. QOLLTI-F v2 contains 17 items across seven subscales (environment, patient condition, carer's own state, carer's outlook, quality of care, relationships, financial concerns) plus one overall QOL item. Items are scored 0–10 with verbal anchors, and one item specifically asks carers about the patient's condition, reflecting its impact on their own QOL [17].

To ensure valid cross-cultural comparisons, it is critical that translated instruments are interpreted consistently. Modern validity frameworks emphasize **response processes**, which capture how respondents perceive, understand, and react to items [19]. Evaluating these processes ensures that translated measures are both linguistically and culturally appropriate, and that scores can be interpreted meaningfully [20]. This study aimed to translate MQOL-E and QOLLTI-F v2 into Swedish and explore content validity and response processes among Swedish patients with life-threatening illness and their family carers.

Materials and Methods

The study involved two sequential phases for each instrument: (I) translation and cultural adaptation, and (II) assessment of content validity and response processes through cognitive interviews.

Translation and adaptation

The instruments were translated following the EORTC protocol [21]. Two independent bilingual translators, native in Swedish, performed forward translations. These were harmonized by the Swedish research team to create preliminary versions, which were then back-translated into English by two independent native English speakers. The original instrument developers reviewed these back-translations, and the research team finalized preliminary Swedish versions after evaluating linguistic and cultural appropriateness.

Content validity and response processes

Cognitive interviews using think-aloud techniques and targeted probing questions were conducted to assess participants' understanding of items and the relevance of content [22, 23].

Participants and recruitment

Participants were adults fluent in Swedish. For MQOL-E, patients had life-threatening illnesses including advanced heart failure (NYHA III–IV), advanced COPD (III–IV), end-stage kidney disease, or advanced cancer in palliative care. For QOLLTI-F v2, participants were family carers of such patients. Purposive sampling ensured diversity in age, gender, diagnosis, and carer–patient relationships. Participants were recruited from outpatient, inpatient, and home care settings of a county hospital in southeast Sweden, including hemodialysis, heart, lung, and specialized palliative care units. Research nurses identified eligible participants, provided study information, and a researcher obtained written informed consent.

Fifteen patients (11 men, 4 women; age 43–84, median 72) participated in MQOL-E interviews, representing advanced heart failure (n=3), COPD (n=4), end-stage kidney disease (n=5), and advanced cancer (n=3). Nine family carers (age 38–77, median 64) participated in QOLLTI-F v2 interviews, including spouses, children, and other relatives. Participants' educational backgrounds ranged from elementary to university level.

Data collection and analysis

Data were gathered through cognitive interviews conducted by two researchers between September 2016 and March 2017. The interviews employed a think-aloud protocol combined with targeted probing questions [23] to explore participants' interpretations and reflections on MQOL-E and QOLLTI-F v2 items, specifically regarding relevance, clarity, and sensitivity of content and wording. Prior to the interviews, participants were briefed on the think-aloud method and encouraged to verbalize their thoughts while completing each item. They were also asked for feedback on item clarity, appropriateness of response scales, content relevance, overall length of the instrument, and whether any important QOL aspects were missing (e.g., "What are your thoughts on the response options? Do you consider the instrument length appropriate? Are there any items you would consider unnecessary?").

Interviews were conducted in quiet locations, either at participants' homes or in the university office, based on participant preference. One patient and one family carer were interviewed via telephone. Patient interviews lasted 23–66 minutes (median = 33 minutes), while family carer interviews lasted 29–85 minutes (median = 57 minutes). All interviews except two with family carers were audio-recorded, and field notes were taken during all sessions.

Analysis of content validity and response processes followed Willis' [23] recommendations for overlapping analytic approaches in cognitive interview research. Analyses were conducted separately for each instrument, beginning after the first interview to identify potential items requiring rephrasing; subsequent interviews tested any modifications. All audio recordings were reviewed (LA, NC) and analyzed alongside interviewer notes detailing participant reactions and behaviors. The analysis focused on relevance, clarity, and sensitivity of content. Responses were coded according to these domains, and codes were compared, discussed, and categorized into pre-defined areas of relevance, clarity, and sensitive wording (LA, NC, AA, KÅ).

Results and Discussion

MQOL-E

Relevance

Participants generally considered the MQOL-E and its items to address important aspects of their QOL. Two patients, currently in a more stable phase of illness, suggested that the instrument might be more applicable at later stages. One patient questioned the relevance of healthcare-related items, though others felt that quality of healthcare remained an important component of their QOL. Several participants expressed a desire for open-ended questions to capture additional personal factors influencing QOL, such as the health of loved ones or concerns for dependents. One patient proposed including an item addressing the impact of others' behaviors (e.g., colleagues or school staff) on their QOL. Overall, participants did not find the instrument burdensome, and completion time was acceptable. When asked, patients indicated that MQOL-E could effectively capture changes over time, making repeated assessments worthwhile throughout the illness trajectory.

Clarity

Instructions were understood by all participants. Some patients referred back to the introductory example for guidance during completion. Most reported that the items were straightforward and easy to answer. However, some items required further reflection: two participants noted that the item on "feeling supported" could be interpreted differently depending on whether it referred to family, friends, or healthcare providers. Some considered "depressed" and "sad" to be synonymous, while others distinguished between the two. Reflecting on "control over life" occasionally required participants to reconcile their serious illness with the 48-hour recall period; these reflections were seen as interpretative rather than translation issues, and no rewording was necessary. Participants also commented on some verbal anchors: "terrified" when considering the future was perceived as too strong, while "extremely good" was questioned in relation to quality of healthcare, though one participant found it appropriate. The 0–10 response scale was generally appreciated, with some participants familiar with it from pain assessments. Others suggested a 0–5 scale might be simpler. Some participants noted inconsistencies in the strength of reversed verbal anchors between items and occasionally responded in reverse of their intended meaning due to these variations.

Sensitive content and wording – patients

Participants did not find any MQOL-E items distressing, offensive, or emotionally overwhelming. Nevertheless, approximately half of the patients displayed emotional reactions while completing the questionnaire, ranging from tears and sadness to moments of joy when reflecting on positive aspects of life. Despite these reactions, none wished to pause or withdraw from the study, emphasizing the importance of participating. Several patients highlighted that reflecting on their circumstances while responding was valuable and meaningful. One participant noted difficulty responding honestly to healthcare-related items due to dependence on providers and suggested that anonymous responses could facilitate more candid answers.

QOLLTI-F v2

Relevance

Family carers reported that QOLLTI-F v2 items accurately reflected their current experiences and captured domains relevant to their QOL. Several carers noted that the instrument was particularly suitable for those caring for patients who were severely ill and receiving home care. Opinions varied on specific items: one carer initially questioned the relevance of financial items but later acknowledged their importance, while another considered them crucial from the outset. The 48-hour recall period posed some challenges; one carer found it too extreme, another observed that some experiences fluctuate hourly, particularly emotional states. Suggestions for additional items included support and information provided by healthcare professionals, feelings of entrapment, and items reflecting the emotional variability of caregiving. Overall, completing the questionnaire was not considered burdensome, and carers reported that repeated completion could help track changes over the illness trajectory and prompt meaningful actions, such as initiating family discussions.

Clarity

Instructions were generally clear. Most items were well understood, although some semantic ambiguities arose. For example, the item "… I was satisfied with the place the family member/friend I'm caring for was staying (home, hospital, other)" was sometimes interpreted as referring to care quality rather than satisfaction with the location. Similarly, "… I had the privacy I wanted" was occasionally understood in terms of work-life balance rather than personal privacy, prompting revisions in the Swedish translation. Additional rewording clarified whether items referred specifically to patient care versus interactions with other family members. Suggestions for adjusting terminology, such as "stressful" in relation to the ill person, were incorporated. The 0–10 response scale was generally clear, though some carers suggested a narrower 0–5 scale might be easier. Variations in the direction of the response scales required careful consideration, as some found it challenging to maintain consistency in interpretation across items.

Sensitive content and wording – family carers

No carers found items upsetting or difficult to manage emotionally. However, some became visibly emotional when discussing their caregiving situation. Reflecting on the items was generally perceived as important and rewarding. Participants highlighted the potential value of discussing responses with a healthcare professional, which could serve both as a means of acknowledgment and support. Preferences varied regarding completion: some carers preferred filling out the questionnaire at home before discussing responses, while others favored having a professional present during completion.

This study reports the Swedish translation and initial validation of MQOL-E and QOLLTI-F v2, companion instruments for assessing QOL in patients with life-threatening illnesses and their family carers. Cognitive interviews explored how respondents interpreted and reacted to items, providing evidence of response processes—a key aspect of measurement validity in a new cultural context [19]. Understanding response processes is critical because cultural differences can influence how items are interpreted, potentially affecting score meaning.

The cognitive interviews demonstrated that both instruments are relevant, comprehensible, and culturally appropriate for Swedish participants. Minor translation adjustments improved clarity without altering item meaning, and participants found completing the questionnaires meaningful and reflective. These findings support the content validity, linguistic equivalence, and cultural suitability of the Swedish versions. The observed relevance aligns with the instruments' development process, which was grounded in qualitative interviews capturing patients' and carers' perspectives on what is important at the end of life [6, 17].

Two patients who were in a relatively stable phase of their illness indicated that the MQOL-E might become more relevant as their condition progressed. Similarly, QOLLTI-F v2 was viewed as particularly applicable for carers of patients receiving intensive home-based care. These observations suggest that both instruments may be most pertinent in later stages of palliative care. However, participants also emphasized that including these items at earlier stages is important for tracking changes in quality of life over time or as the disease evolves.

Suggestions for additional MQOL-E items focused on the influence of others on patients' quality of life, highlighting the role of social interactions and relationships at the end of life. Originally, MQOL included an item assessing whether "the world has been: an impersonal, unfeeling place vs. caring and responsive to my needs," but it was replaced with an item concerning "people I care about…" because some participants found "the world" too abstract.

Family carers proposed that QOLLTI-F v2 could be supplemented with items addressing specific caregiving challenges, such as receiving information from healthcare professionals. This aligns with previous research identifying the need for carers to understand what to expect in the future [24–26].

For both instruments, these suggested additions underscore that quality of life is highly individualized, with different aspects carrying varying levels of importance [27]. Overall, participants found the instruments relevant, meaningful, and engaging. In line with best practices in instrument development, decisions must balance content coverage with respondent burden [28]. One potential solution for incorporating additional topics without lengthening the instruments is to allow participants to provide free-text comments [29].

Some carers found the 48-hour recall period in QOLLTI-F v2 challenging—both because it was too short or constraining, and because certain experiences fluctuate hourly. This variability reflects the unstable nature of quality of life in life-threatening illness and must be considered when interpreting scores. The original developers chose a 48-hour timeframe to capture this short-term variability, rather than the more typical weekly or monthly timeframes [6, 17]. Nonetheless, extreme events during the last 48 hours may influence scores and should not be generalized to longer periods.

A few participants suggested narrowing the response scale from 0–10 to 0–5. However, during development, a 0–10 scale was deemed intuitive and acceptable, which was confirmed in this study (Cohen, personal communication). Some noted that the verbal anchors at either end of the scale varied in intensity, but this variation was deliberate to improve score distribution, particularly since extreme negative anchors were seldom chosen in earlier studies (Cohen, personal communication).

Both patients and carers occasionally responded in the opposite direction of their intended answer when items had reversed scales. This phenomenon is challenging to eliminate due to differences in how individuals interpret "10"—either as "the most" of something (positive or negative) or "the best." Previous research indicated that reversing response scales does not introduce sufficient bias to justify altering them [30]. To maintain comparability with the original instruments, the Swedish versions retained the original scale directions.

Participants frequently displayed emotional reactions, including sadness and joy, when reflecting on items. This underscores the importance and relevance of MQOL-E and QOLLTI-F v2 content, and suggests that responding can provide opportunities for self-reflection and emotional expression. The instruments may also facilitate meaningful conversations about quality of life between patients, family carers, and healthcare professionals. In particular, QOLLTI-F v2 could help carers communicate their own experiences and feel recognized by care providers, which is a core component of palliative care. Finally, previous research has shown that participation in studies can be meaningful and valuable for vulnerable populations, including patients nearing the end of life [31] and their family members [32, 33].

Methodological considerations

The study included patients with a range of life-threatening conditions, including advanced heart failure, advanced chronic obstructive pulmonary disease, end-stage kidney disease, and advanced cancer. Participants were recruited from diverse care settings—outpatient, inpatient, and home care—which strengthens the generalizability of the findings. In cognitive interview research, the number of participants required depends on study objectives and the depth of data obtained [23]. Purposive sampling ensured variation in age, gender, education, and family relationships, adding richness and diversity to the dataset. Moreover, the interviews produced repetitive information, suggesting that the sample size was sufficient to explore content validity and response processes. Nonetheless, it is possible that perspectives from individuals who declined participation may differ from those included. Detailed reporting of participant characteristics and study findings aids in evaluating the transferability of results to other contexts.

Patients were at different stages of illness, ranging from more stable periods to the end of life, although those completing the MQOL-E were not in the final days or weeks of life. This could influence how they perceived the relevance of certain items, as QOL priorities may shift with disease progression. While participants indicated that the instruments could capture changes over time, actual longitudinal validation in Swedish remains to be confirmed. Additional studies are required to provide psychometric evidence of measurement equivalence and sensitivity to changes over time for the translated instruments [34].

This study focused on translating and validating an interim version of MQOL-E and version 2 of QOLLTI-F. Since the study, a fully validated version of MQOL-E has been published, excluding item 20 (Availability of health care), with no further modifications [9]. Similarly, QOLLTI-F version 3 has removed item 13 (Availability of health care). Therefore, the current validation remains relevant for the most recent versions of both instruments.

Conclusion

This study provides valuable evidence regarding response processes for MQOL-E and QOLLTI-F v2, particularly concerning linguistic equivalence and cultural appropriateness of the Swedish translations. The findings highlight the importance of investigating how respondents interpret and engage with questionnaire items when developing or adapting instruments across languages and cultural contexts. Further psychometric evaluation of the Swedish versions is necessary before definitive recommendations can be made for their use in palliative and end-of-life care. Given that both instruments are designed for use regardless of underlying diagnosis and can function as companion measures, they hold significant potential for application in both clinical practice and research settings.

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